General

Title

Epilepsy: percentage of children with epilepsy who were commenced on antiepileptic drugs referred for input by an epilepsy specialist nurse by 1 year.

Source(s)

The Royal College of Paediatrics and Child Health. Epilepsy12 national report, round 2. London (UK): The Royal College of Paediatrics and Child Health; 2014 Nov. 103 p.

The Royal College of Paediatrics and Child Health. Epilepsy12, round 2. Full methodology document. London (UK): The Royal College of Paediatrics and Child Health; 2013 Jun. 33 p.

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Process

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the percentage of children with epilepsy who were commenced on antiepileptic drugs, referred for input by an epilepsy specialist nurse by 1 year.

Rationale

Epilepsies are amongst the most common significant long-term health conditions of childhood and pose significant challenges for the National Health Service. The Epilepsy12 audit has demonstrated significant improvement in care during its first five years.

Evidence of input is important for children with epilepsy but even more important for those receiving antiepileptic drugs (AEDs) therefore split into 2 subgroups.

Recommendations

Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of individuals with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the individual, families, carers and, in the case of children, others involved in the child's education, welfare and well-being (National Institute for Health Clinical Excellence [NICE], 2012).

Each epilepsy team should include paediatric epilepsy nurse specialists (Scottish Intercollegiate Guidelines Network [SIGN], 2005).

Evidence for Rationale

National Institute for Health and Clinical Excellence (NICE). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jan. 117 p. (Clinical guideline; no. 137).

Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsies in children and young people. Edinburgh (Scotland): Scottish Intercollegiate Guidelines Network (SIGN); 2005 Mar. 53 p. (SIGN publication; no. 81). [279 references]

The Royal College of Paediatrics and Child Health. Epilepsy12 national report, round 2. London (UK): The Royal College of Paediatrics and Child Health; 2014 Nov. 103 p.

Primary Health Components

Epilepsy; antiepileptic drugs (AEDs); epilepsy specialist nurse; children

Denominator Description

Number of children diagnosed with epilepsy as defined who were commenced on antiepileptic drugs (AEDs) at any time during first year (see the related "Denominator Inclusions/Exclusions" field)

Numerator Description

Number of patients diagnosed with epilepsy as defined who were commenced on antiepileptic drugs (AEDs) who had input from or referral to an epilepsy specialist nurse (see the related "Numerator Inclusions/Exclusions" field)

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Unspecified

Extent of Measure Testing

Epilepsy12 Round 2 is the second cycle of this audit which aimed to re-examine the quality of care for children and young people with epilepsies in the United Kingdom (UK).

Clinical Audit Key Findings

In the Clinical Audit Domain 12 clinical performance indicators were applied to a cohort of 3,449 children for whom a 'first paediatric assessment' for a 'paroxysmal episode or episodes' was undertaken during the four months between 1 January and 30 April 2013. In Round 1 the cohort was identified similarly but across a six-month period from 1 August 2009 to 31 January 2010.

Clinical Audit Performance Indicator Key Findings

Ten of the 12 performance indicators were defined identically to those used in Round 1 and were applied to a similarly defined cohort of children in Round 2. Of the 10 clinical performance indicators where longitudinal comparison was possible across rounds, 9 indicators showed a statistically significant improvement across the UK (tertiary involvement being the exception–point 3 on the chart). The 12 performance indicators results for both rounds are summarised in the original measure documentation.

Recruitment

The audit covered England, Northern Ireland, Scotland and Wales. All paediatric services that employ NHS paediatricians that request electroencephalograms (EEGs) and are involved with the care of children and young people with seizures or epilepsy were invited to participate. During Round 1, the UK was split into pragmatic regions and 'audit units'. Each 'audit unit' had defined: Consultant Paediatricians (one of whom acting as the audit unit lead); National Health Service (NHS) Health Boards, Trusts; Hospitals; Community Paediatric services and EEG services. Audit units invited to participate in Round 1 were also invited to participate in Round 2.

Data and Quality Analysis

The data collection system included validation rules to ensure that appropriate and internally consistent data was provided by the participating units. This meant that the overall data quality standard was high. Six records were removed from the dataset as the first paediatric assessment had taken place when the child was less than one month old or an implausible age at first paediatric assessment was recorded. Audit units were able to view provisional data and provide corrected data where appropriate.

The Epilepsy12 indicators are reported with 95% confidence intervals. The Wilson score method has been used to calculate confidence intervals. The confidence intervals can be used to assess whether there has been a statistically significant change in between Round 1 and Round 2 or between countries. If the 95% confidence intervals do not overlap the difference is statistically significant. Individual Audit Units are identified as a positive outlier (statistically significantly higher than the UK value) if the unit's upper 95% confidence interval is below the lower confidence interval for the UK. This is equivalent to being approximately two standard deviations above the UK value. Units are identified as a negative outlier (statistically significantly lower than the UK value) if the unit's lower 95% confidence interval is above the upper confidence interval for the UK. This is equivalent to being approximately two standard deviations below the UK value.

Refer to the original measure documentation for performance indicator results and key findings.

Evidence for Extent of Measure Testing

The Royal College of Paediatrics and Child Health. Epilepsy12 national report, round 2. London (UK): The Royal College of Paediatrics and Child Health; 2014 Nov. 103 p.

State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Ambulatory/Office-based Care

Ambulatory Procedure/Imaging Center

Emergency Department

Emergency Medical Services

Hospital Inpatient

Hospital Outpatient

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Clinical Practice or Public Health Sites

Statement of Acceptable Minimum Sample Size

Unspecified

Target Population Age

Age greater than 1 month and less than 16 years

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Prevention and Treatment of Leading Causes of Mortality

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

Getting Better

Living with Illness

IOM Domain

Effectiveness

Data Collection for the Measure

Case Finding Period

1 January to 31 October

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Clinical Condition

Diagnostic Evaluation

Encounter

Patient/Individual (Consumer) Characteristic

Therapeutic Intervention

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions
Number of children diagnosed with epilepsy as defined who were commenced on antiepileptic drugs (AEDs) at any time during first year

Clinical Cohort Ascertainment: An initial heterogeneous group will be identified from electroencephalogram (EEG) services who will identify the potentially eligible group by identifying all children referred for a first EEG between 1 January and 31 October 2013. The EEG service will forward a list of all cases identified on a monthly basis to the audit unit lead who will filter the cases to form the cohort by application of inclusion and exclusion criteria. Refer to the original measure documentation for additional information.

Inclusion Criteria:

- First EEG between 1 January and 31 October 2013.
- The child has a 'first paediatric assessment' for the 'paroxysmal episode or episodes' between 1 January and 30 April 2013.
- Child is older than 1 month and younger than 16 years at 'first paediatric assessment'.
- The EEG was prompted by the patient having one or more afebrile paroxysmal episodes.

Note:

- *Epilepsy*: A chronic neurological condition characterised by two or more epileptic seizures (International League Against Epilepsy [ILAE]). A pragmatic definition for epilepsy in this audit is 2 or more epileptic seizures more than 24 hours apart that are not acute symptomatic seizures or febrile seizures.
- *AEDs*: Regular daily drug treatment for reduction of risk of epileptic seizures in epilepsy. Not including drug treatment given for during a prolonged seizure (e.g., rectal diazepam/paraldehyde, buccal midazolam, intravenous [IV] lorazepam/phenytoin) or clusters of seizures (e.g., intermittent clobazam). Not including drugs where the purpose of treatment is for something other than epilepsy treatment (e.g., carbamazepine [CBZ] for behaviour, topiramate for migraine, etc.)
- *First Paediatric Assessment*: A 'face to face' assessment by a secondary level/tier doctor in a paediatric service occurring in any non-acute or acute setting. Assessment within emergency department (ED) counts if performed by paediatric team rather than an ED team. Some paediatric neurologists see referrals direct from GP or ED and these would count as both a first paediatric assessment and tertiary input.
- *Paroxysmal Episodes*: This is the term chosen in this audit to represent the events causing concern. It includes all epileptic and non-epileptic seizures and also seizures of uncertain origin.

Exclusions

- All 'paroxysmal episodes' in question were diagnosed as 'febrile seizures'. (Children with a history of febrile seizures being assessed for different afebrile 'paroxysmal episodes' may be included.)
- The patient has had a paediatric assessment previously for similar episode or episodes or epilepsy prior to first paediatric assessment.
- All the paroxysmal episodes that the patient had were acute symptomatic seizures or occurred within a week of a traumatic head injury.
- The patient's care was permanently transferred to a secondary paediatric service outside the 'audit unit' boundaries or an adult service during the year after first paediatric assessment.

Note:

- *Febrile Seizure*: An episode diagnosed by the assessing team as a 'febrile seizure' or 'febrile convulsion' or 'febrile fit'.
- *Acute Symptomatic Seizures*: Seizures occurring at the time of a diagnosis of an acute disorder (e.g., meningitis, encephalitis, electrolyte disturbance, etc.).
- *Audit Unit*: One or more secondary tier paediatric services grouped together using pragmatic boundaries agreed by the paediatric audit unit link, the project team and the tertiary link.

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions

Number of patients diagnosed with epilepsy as defined who were commenced on antiepileptic drugs (AEDs) who had input from or referral to an epilepsy specialist nurse

Note:

- *Input*: Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact.
- *Children's Epilepsy Specialist Nurse*: A children's nurse with a defined role and specific qualification and/or training in children's epilepsies.

Exclusions

Unspecified

Numerator Search Strategy

Fixed time period or point in time

Data Source

Electronic health/medical record

Paper medical record

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Unspecified

Computation of the Measure

Measure Specifies Disaggregation

Does not apply to this measure

Scoring

Rate/Proportion

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

2b. Percentage of children with epilepsy who were commenced on AEDs, referred for input by an epilepsy specialist nurse by 1 year.

Measure Collection Name

Epilepsy12 Performance Indicators

Measure Set Name

Involvement of Appropriate Professionals

Submitter

Royal College of Paediatrics and Child Health - Medical Specialty Society

Developer

Royal College of Paediatrics and Child Health - Medical Specialty Society

Funding Source(s)

Unspecified

Composition of the Group that Developed the Measure

Project Board

- Dr. Helen Basu, Consultant Paediatric Neurologist, British Paediatric Neurology Association representative
- Alex Bird, Development Officer, Healthcare Quality Improvement Partnership
- Ann Brown, Epilepsy Specialist Nurse, Royal College of Nursing representative
- John Cowman, Director of Operations, Young Epilepsy
- Dr. Colin Dunkley, Consultant Paediatrician, Project lead
- Dr. Colin Ferrie, Consultant Paediatric Neurologist, Clinical representative
- Jacqueline Fitzgerald, Director of Policy and Research, RCPCH
- Dr. Martin Kirkpatrick, Consultant Paediatric Neurologist, Scotland and HIS representative
- Dr. Katherine Martin, Consultant in Paediatric Neurodisability, British Academy of Childhood Disability representative
- Dr. Lesley Notghi, Consultant Neurophysiologist, British Society for Clinical Neurophysiology representative
- Angie Pullen, Epilepsy Services Manager, Epilepsy Action
- Dr. Yvonne Silove, Associate Director for Quality and Improvement, National Clinical Audit and Patient Outcomes Programme, Healthcare Quality Improvement Partnership
- Anissa Tonberg, Policy and Development Manager, Epilepsy Scotland
- Berni Waldron, Epilepsy Specialist Nurse, Audit Facilitator

Methodology Working Group

- Katherine Bowyer, Neurophysiological Scientist
- Dr. Richard Chin, Consultant Paediatric Neurologist
- Dr. Colin Dunkley, Consultant Paediatrician
- Dr. Colin Ferrie, Consultant Paediatric Neurologist
- Dr. Katherine Martin, Consultant in Paediatric Neurodisability
- Berni Waldron, Epilepsy Specialist Nurse
- Dr. William Whitehouse, Senior Lecturer in Paediatric Neurology

Financial Disclosures/Other Potential Conflicts of Interest

No financial disclosures or potential conflicts of interest

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2014 Nov

Measure Maintenance

Measures are reviewed with consideration for update as national recommendations are updated and the audit cycle is repeated. This frequency will be removed as the audit evolves to continuous audit models.

Date of Next Anticipated Revision

2017

Measure Status

This is the current release of the measure.

Measure Availability

Source available from the Royal College of Paediatrics and Child Health (RCPCH) Web site:

- Epilepsy12 national report, round 2.
- Epilepsy12, round 2. Full methodology document.

For more information, contact RCPCH at 5-11 Theobald's Road, London WC1X 8SH, UK; Phone: +44 (0)20 7092 6000; E-mail: epilepsy12@rcpch.ac.uk; Web site: www.rcpch.ac.uk/.

NQMC Status

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Copyright Statement

Production

Source(s)

The Royal College of Paediatrics and Child Health. Epilepsy12 national report, round 2. London (UK): The Royal College of Paediatrics and Child Health; 2014 Nov. 103 p.

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